To: Public Health Committee on proposed bill 5747 to reinstate positive Lyme disease cases.

From: Maggie Shaw RN, Newtown Lyme Disease Task Force

82 Eden Hill Road, Newtown, CT 06470 203-270-1834

Dear Public Health Committee Members,

I am very grateful for this opportunity to testify in support of bill 5747 to reinstate mandatory lab reporting in the state of CT for positive Lyme disease cases. I am a registered nurse in the state of CT, my entire family of five are infected with tick-borne diseases that were left undiagnosed and untreated for too many years due to lack of knowledge among physicians in CT on late stage manifestations of Lyme and the unreliability of testing. We now face a more difficult treatment due to this delay in diagnosis. Please consider the fact that the bacteria that causes Lyme is a spirochete very closely related to syphilis and the effects syphilis has on the body and brain and difficulty in treating late stage.

I am presently chair of the Newtown Lyme Disease Task Force, initiated in the year 1999-2000 out of growing concern for the increasing incidence of Lyme disease among Newtown residents.

One of our first initiatives was to create an informal survey. Close to 400 signatures collected from Newtown and surrounding areas regarding concern and number of residents infected revealed to us that:

-2/3 of individuals reported having personally had Lyme disease or having someone in their family who are/have been infected.(enclosed)

-In 1999 a survey by Danbury Hospital regarding health concerns of area residents ranked Lyme disease number one among callers for five consecutive years.(enclosed)

-In 2001, the Wilton Task Force on Lyme Disease commissioned a survey. Millward Brown, the largest worldwide supplier fo consumer research was asked to check the incidence of Lyme disease in Wilton, Newtown and Ridgefield. This survey discovered that 39% of households in these three towns have some member who has been diagnosed with LD. The highest incidence was in Wilton 44%, followed by Newtown at 38% and Ridgefield at 36%. Of those diagnosed, 64% had a positive blood test and 66% had a rash. According to survey results, therefore 4 in 10 households had a member diagnosed with Lyme disease or 1 in 5 people in these towns. Of those diagnosed, almost one quarter said they had lingering health problems. This is equivalent of 5% of the towns' total population suffering from the lingering.

-Several other communities have also conducted surveys, Wilton's Deer Committee found 54% of those surveyed reported at least one diagnosed case of LD in their household. Over one third reported multiple cases in that time frame. Three out of ten reporting diagnosed cases said that these involved symptoms lasting more than 6 months.

Statistics and reported cases from Newtown Health District Manager, Donna Culbert, MPH

the last three years have all been physician reports, there have been a few labs that came in as a follow-up to the physician report, but no labs came in by themselves.

2004 had 25 Lyme Disease, 10 Babesiosis and 5 Ehrlichiosis (I know the name has changed)

2005 had 34 Lyme Disease, 10 Babesiosis and 14 Ehrlichiosis

2006 had 25 Lyme Disease, 29 Babesiosis and 28 Ehrlichiosis

There were two co-infections of babesia and ehrlichia and one co-infection of Lyme and Babesia - its not reported to me that way, I just compared the names on the reports.

I am not aware of labs on-line that are reporting. If they are, I don't know about it.

Tick infection rates:

2004 positive 43%

2005 positive 29%

2006 positive 23% note: New CAES requirement: 2006 ticks were only tested if they had fed on blood; 142 unengorged ticks were submitted but not tested.

These surveys and statistics express the warranted concerns of the people and the number of people impacted and infected by this disease and clearly points to the prevalence of LD in CT.

Residents of Connecticut are at the epicenter of a significant public health threat. Lyme and other tick-borne diseases are spreading rapidly throughout CT and nationwide. The growing number of advocates, support groups and task forces is a huge testimonial to the pain and suffering that Lyme is inflicting upon our state.

To address concerns expressed by both patients and medical personnel, a hearing was held in CT on January 29th, 2004 by Public Health Commissioner Robert Galvin, MD and Attorney General Richard Blumenthal. Researchers, clinicians, patients and government officials assembled to exchange information in an open forum designed to increase understanding of Lyme disease. There was an overflow of attendance.

At the hearing Commissioner Galvin indicated that the cessation of laboratory reporting would not affect the public health because the seriousness of the disease in CT was well known and resources would be better utilized in a broader prevention program. DPH suggested that any decline would be quickly offset by the implementation of an electronic reporting system that was to be fully operational in accordance with Homeland Security directives by the summer of 2005. Electronic surveillance has not been established and the broader prevention program is limited to two health districts, there is no statewide education or awareness and no alerts warning the citizens of CT of the dangers of ticks and the diseases they carry.

The recent statistics provided in the Connecticut Epidemiologist show a significant decline in

Lyme disease cases in 2005. This information was provided to the media and public without reason for the decline and did not make mention that it had nothing to do with infection rate but rather to do with the system of reporting and the cessation of laboratory reports. This sends a very unclear message to physicians, public and media alike. Rates would have been significantly higher in 2005 than in 2003 had lab reporting still been in place

The commitment to address the concerns of the citizens, physicians and public health officials to reinstate laboratory reporting of Lyme have been rejected and commitments to include Lyme as a Lab reportable finding have been ignored. The DPH by this lack of initiative is minimizing the impact of Lyme on the public health in CT. The Health Department is under reporting and understating the number of Lyme disease cases which is misleadingly reassuring the public.

The mission of the Epidemiology and Emerging Infections Program at the DPH is to prevent illness, disability, and death in CT caused by infectious disease. Epidemiology is the branch of medicine dealing with the incidence and prevalence of disease and cause of disease in mankind. How is this possible if there is not a stable, accurate means of measurement to ensure we are assessing the rates and trends across the state and not limited to two health districts in the state.

Historically physicians only report 20% of cases while labs report 80%.

- -Physicians are not reporting cases: in 2001 and 2002 in Newtown only 22 physician reports in those two years in Newtown.
- -584 Lab reports of confirmed Lyme disease from Newtown alone during that same 2 year period-very stringent requirements to meet threshold for lab criteria.

Even before mandatory lab reporting was discontinued, the DPH acknowledged in public hearings and in their published research that physicians in CT are under reporting:

"Survey results suggested that, at best, only 16% of Lyme disease cases were reported in 1992. Physician under reporting of Lyme disease underestimates the public health impact of Lyme disease." (Meek et al., 1996) **enclosed article**

Dr. Matthew Cartter of the DPH acknowledged this problem at the public hearing for legislation of Lyme disease coverage by insurance companies in 1999. (http://www.ct.gov/ag/cwp/view.asp?A=1774&Q282848):

"We are very much aware that what's reported to us in only a fraction of what's out there." (p.17)

"We estimate that the number of cases that are reported to us and meet the surveillance case definition are probably only 10 to 25% of all the cases that occur." (p.18)

"We estimate that for every case that's reported to us that meets the national surveillance case definition, there's probably another nine of 10 people out there who are diagnosed by a physician to have Lyme disease and treated for that disease." (p.22)

1. At present, Matthew Cartter has been receiving Federal funds for community and intervention programs on Lyme since 1999. Most recent grant title as follows.

Prevention of Lyme Disease in Connecticut, Matthew Cartter, M.D., M.P.H., Connecticut Department of Public Health, Hartford, Connecticut. This study will evaluate the effectiveness of integrated prevention measures to reduce the risk of Lyme disease in the United States, and will evaluate the costs of these interventions in relation to the number of cases prevented.

Laboratory surveillance is critical for the analysis of data collected from this Federally funded project. From both a state level and national level. Progress can not be established on the effectiveness of integrated prevention measures to reduce risk of Lyme disease, CT can not establish the costs of interventions in relation to the number of cases prevented. Can the surveillance methods statistically support that intervention efforts are having a good effect? Connecticut is the only state in the country that is funded by the CDC for this activity. It is imperative that this program not only provide CT with the effectiveness fo these programs but nationally as well and therefore the most accurate of reporting systems must be utilized. Connecticut not only has a state responsibility but a national on. With this Federal funding we need a counting system that would be the most effective, valid and reproducible to facilitate national programs.

If the laboratory surveillance was implemented for Federally funded vaccine trials, it would stand that this is the most comprehensive methodology for counting.

At the 2004 Hearing, James Hadler, MD, MPH, director of the DPH Infectious Disease Department stated that currently only four states are funded for Lyme disease surveillance and prevention, CT being one. Yet there are other states who are not CDC funded that have mandatory lab reporting to count LD cases, because the CDC shifted its priorities does not mean that would should stop counting, which is a very high priority in a state rampant with Lyme.

Lyme cases in 2005 increased 34%, tick infection rates and deer population growth are escalating with no limit in site. Little if any education materials to citizens, schools, towns, physicians, or health districts alerting citizens to the dangers of tick-borne diseases. Lack of Lyme Curriculum in schools. The number of children on IEPs and 504s due to physical or cognitive impairment related to Lyme are increasing. Children missing weeks, days and months of school and too many are walking the halls with IVs or PICC lines for long-term antibiotic treatment.

For the past two years online results of tick infection rates are not available at the Connecticut Agricultural Experiment Station website. Further inhibiting information on the rise fo infected ticks throughout CT towns. The CAES is funded through the same grant provided by DPH in a collaborative effort.

2. Public, physician, media and medical professional perceptions on prevention measures that are taken to reduce risk and increase awareness are greatly measured by quantitative statistics. With out the most accurate measures to insure statistics are seen as increasing and not decreasing the

public will not take appropriate intervention measures. The residents of CT addressed concerns regarding the lack of laboratory surveillance at the 2004 Hearing and in petitions mailed to Commissioner Galvin. Lab reporting is necessary to gauge the efforts of DPH and their sincerity to the public. As residents of CT and to the grass-roots efforts, citizens need numbers to affect the public's ability to demand public funding.

- 3. Additional Federal funding can not be validated based on present surveillance methods, numbers of LD cases do count. The underestimating of this disease will give false impression that LD cases are on the decline. The false decline could greatly impact qualifications for Federal funding based on need. This will not only set back efforts to prevent and protect citizens of CT but across the country. National decline due to CT decrease.
- **4.** The "Perspectives on Lyme Disease Hearing" held in 2004 was a measure to aid in communication between citizens, represented by AG Blumenthal and Commissioner Galvin of the DPH. All panelists spoke of Lyme as being a very serious disease and the vast majority stating that surveillance was crucial to all aspects of this disease.
- 5. Accurate surveillance is needed to follow the course of an infectious disease which is a public health concern and that can vary in incidence with changes in environmental factors, host population, personal prevention measures(which vary based on educational awareness) and population control measures(TAHD). Towns outside fo the control district need to be provided and to be aware of their incidence of disease to provide and protect the people within these communities.

Personal History

In the summer of 1999 my entire family of five after many years of suffering with a myriad of symptoms were diagnosed with Lyme and other tick-borne diseases for many years.

My daughter in that fateful summer of 1999 received a tick bite. It was so small I am truly amazed I found it but I marked down the date in my calendar and started watching for the bulls-eye rash (Taylor was the only person in my family to have classic bulls-eye, many people do not get or do not see). Approximately one month later she had fever, malaise, weight loss, fatigue and a malar rash (rash across cheeks and nose). She was very sick and at the pediatricians I questioned Lyme disease. I had just been diagnosed and was on IV, my son had just been diagnosed after being misdiagnosed by them based on test results and his disease also allowed to progress and he suffered as no child should have to. As I questioned him his response was "I can't understand why people are losing sleep over Lyme disease." No it was not Lyme disease, it was swimmer's ear, sun rash and he did not know what fever was from. Please note this was summer in Connecticut peak time for Lyme disease. The next morning still feverish Taylor awakened with seven bulls-eye rashes on her body, one the size of a baseball. I brought her back to the pediatrician. He diagnosed her with Lyme disease and said you "you learn something new everyday." I asked what would have happened to my daughter had she not had the rashes, his response "I do not know."

Taylor is the only member of my family who would be counted for meeting CDC case definition, she did have EM rash greater than 5cm which is enough to meet definition but she also meet lab criteria which is five bands on the IgG Western Blot.

At this point I began to question the knowledge base of our local doctors. Why were they not aware of the CDC Federal Advisory stating that Lyme disease is a clinical diagnosis and tests should be used as supportive data. This ignorance led to my family suffering for many years undiagnosed and untreated. It was not only my family but my neighborhood where many people had been already diagnosed for Lyme or ehrlichiosis, some already on IV therapy. Exploring further I was beginning to realize it was difficult to go anywhere without meeting someone who had contracted Lyme, was being treated for it or had family members sick.

My first action was to call our local HD and ask why so many people are becoming infected where were the warnings and education.

I was very concerned because there were no programs to alert, educate or inform the residents of CT and most like my family were not aware of the very serious dangers that the ticks and the diseases they transmit presented to us.

The Newtown Lyme Disease Task Force is a grassroots, all volunteer organization whose mission is to provide education and awareness on tick-borne diseases and how to prevent and protect yourselves. Most if not all of our members have late stage Lyme or have children or family members with.

We have provided Newtown a valuable public health service and are known for our joint efforts with the Newtown Rotary Club for our informational seminars. It is not unusual to have over 300 attendees. I believe this is growing testimonial to the need and want of further education among the public.

We also raised and donated funds to the Newtown School System to initiate the MaxForce Bait Box system to protect the children on school grounds

It was very shocking for us to learn that:

- -In the year 2001 and 2002 school year, Newtown public school nurses removed 205 tick attachments from children
- -In that same two year period close to 100 cases of Lyme disease were reported to school officials.
- -The school system has had a handful of students on IVs or IV PICC lines for long term antibiotic treatment.
- -During early July 2002, reported to us by HD, **52% of all ticks** brought into the Newtown Health District carried the bacteria that causes Lyme disease.
- -In one year as reported to NLDTF by Superintendent Pitkoff their were 7-8 children on Individual Educational Programs due to physical or cognitive impairment due to Lyme disease.

Lyme disease should be a priority in the state of CT...most people are infected in their own

backyards. Most people may never even see the tick that infected them. CT and the CT DPH must take responsibility and immediate proactive measures to alert the public and and to stop the spread of this disease that is devastating the lives of our children, families and neighborhoods.

Sincerely,
Maggie Shaw

September 16, 2000

Dear Mr. Rosenthal (First Selectman, Newtown, CT), Mr. Cooper (Director of Health, Newtown, CT), Dr. Draper (Health Advisor, Newtown, CT) and other

elected and appointed officials of our town, state and federal government.

As concerned citizens of the state of Connecticut we are petitioning that measures be instituted immediately to stop the growing epidemic of Lyme disease and other tick-borne diseases in our community and state. We are witnessing an increase in frequency the number of Lyme disease cases among our families, friends and neighbors.

positive for Lyme disease was 19-20%. As of June 2000 the percentage of ticks testing positive was 24%. Statistics are showing that the number of ticks testing positive for the bacteria that causes Lyme disease is increasing, but most importantly are the increasing numbers of cases of Lyme disease throughout our state Last year, 1999, then number of ticks submitted by the Newtown Health District to the CT Agricultural Experiment Station in New Haven, CT that tested and nation. Many, many people in our community are infected and ill, some chronically. Sadly many are misdiagnosed with other diseases that Lyme disease may mimic. Our children run the greatest risk of infection and are therefore in need of the greatest protection.

Physicians on the front lines of this illness admit that we are in our infancy in understanding Lyme disease. Controversy surrounds diagnosis, treatment

and a cure, which makes Lyme disease a dangerous entity.

We are holding our local, state and federal officials accountable for the prevention, education and awareness of the citizens of Connecticut. We desperately need funding for research and a cure for the many infected by this debilitating disease.

Therefore, the reason for this petition is that something must be done immediately to eradicate Lyme disease.

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Oct 1999

Survey Shows Health Concerns Of Area Residents

DANBURY - Questions about Lyme disease, hepatitis and diabetes are the top three health concerns of residents in the Greater Danbury area, according to a survey released

by Danbury Hospital.

The hospital's "Call-A-Nurse" program, a free telephone hotline service offered to the community to answer its health questions, reports that in the past five years, questions about Lyme disease ranked number one among callers. The program released its survey in conjunction with its fifth anniversary.

Callers often ask what the symptoms of the disease are, as well as how to tell if a tick carried the virus. "We often talk to tallers about Lyme disease, especially during the spring and summer," said Lois Benis, manager of Care Management. "It's especially important now as more local residents are worried about the fear of getting encephalitis from insect bites," she adds.

The "Call-A-Nurse" program is a toll-free hotline (800/486-3508) answered by registered nurses at Danbury Hospital. The line is open from 8 am to

4:30 pm weekdays. Callers can talk to a registered nurse in English, Spanish or Portuguese about their health questions. In addition, the nurses can provide information about physician specialists in the community.

Hepatitis and diabetes questions were also reported more often than anything else, according to Ms Benis. Callers wanted to know if they were at risk for contacting hepatitis, as well as why their infant had to be immunized against hepatitis B. Calls about diabetes ranged from how to tell if you had the disease to what type of diet to eat. Calls about asthma, cholesterol and insect bites were also popular.

The top 25 health concerns of residents in the Greater Danbury area, ranked in order, include Lyme disease, hepatitis, diabetes, asthma, low cholesterol diet, insect bites, constipation, back pain, Alzheimer's disease, breastfeeding, infant sleep patterns, fever, flu, cold symptoms, sore throat, chickenpox, head lice, earache, diverticulitis, migraines, tetanus, osteoporosis, osteoarthirtis, herpes, and

Fighting Lyme Disease With Tick Bait Boxes

By Jan Howard

The Lyme Disease Task Force and WIN (Women Involved in Newtown) are spearheading efforts to raise money for a new product for school properties that fights the ticks that cause Lyme disease.

The product, the Maxforce Tick Management System, is used to kill ticks on mice and chipmunks and reduce the tick population that causes Lyme disease.

Kim Harrison and Maggie Shaw of the Lyme Disease Task Force and Mandy Monaco of WIN this week announced an effort to raise funds to help pay for bait boxes recently installed at two of the elementary schools.

"It's a brand new product," Ms Harrison said. The cost for bait boxes at the two elementary schools will be about \$4,000. She added that Superintendent of Schools John Reed has been very supportive of the effort and agreed to have the school system pay for the bait boxes. She initiated the fundraising effort to help the schools with the cost.

"Hopefully in the future it will come out of the school budget," Ms Harrison said.

Ms Shaw said she believes tick control efforts will continue in the schools because parents will realize their children are more protected through these programs.

Ms Harrison recently approached WIN and Newtown Newcomers, which each donated \$500 toward the cost of the bait boxes. WIN has also provided 100 signs for placement in town parks and forest areas to advise the public of deer tick habitat.

"I'm planning to speak to as many organizations as I can," Ms Harrison said.

She also plans to send out a fundraising letter. "We have to address the other schools," she said. "This will be on an ongoing basis as we learn more.

"We're happy with how our town is moving ahead," she added

Richard Whitman of Connecticut Tick Control donated ten bait boxes for installation at the schools. Mr Whitman's company is the only one in Connecticut currently offering the boxes. Mr Whitman was part of the research and development team that tested the product with its inventor, Aventis Environmental Science of Montvale, N.J.. He said a homeowner video wou 1 be available in the future, supp-lied by Connecticut Tick Control or Aventis.

Mr Whitman, who has donated his time as a consultant for the task force, has worked with several towns and government agencies to educate the public about Lyme disease and tick control methods. He has been involved in public education on Lyme disease for five years.

Residents or organizations interested in contributing to the fundraising effort should send checks earmarked for the bait box fund to WIN, PO Box 286, Newtown, CT 06470. The cost per bait box is \$40.

First Selectman Herb Rosenthal recently provided funds from the town budget to install bait boxes at Dickinson and Treadwell parks. Ms Harrison also praised the efforts of Supervisor of School Buildings and Grounds Dom Posca for landscape modifications at the schools.

"Dominic has been phenomenal," she said, in doing spraying, landscaping, and wood chipping, and assessing the situation on how to improve tick control methods at the schools.

"The schools need to be taken care of," Ms Harrison said, noting, however, that not all the schools need bait boxes.

"It depends on the size of the school and the area," Mr Whitman said. "Some of the schools are bordered by grass areas or stonewalls. Property management will do in those cases."

Ms Shaw said that as part of property management the school maintenance personnel are now collecting leaves rather than blowing them into the woods.

"Everyone is working together to protect our kids," Ms Harri-

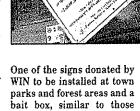
"Making Newtown a tick-safe town is our goal," Ms Shaw said. "We'll be a model for other communities."

Mr Whitman said only a handful of school systems are doing anything more than property management. "This is the beginning. Every municipality will have to address this sooner or later," he noted.

Though property management, spraying, and bait boxes will help make the community safer, Ms Shaw said, "There are still a lot of ticks out there." People need to be informed about when ticks are out and where they are, she noted.

She said the fundraising effort "will help create an understanding of how important it is and how serious the disease is. You still need daily tick checks and proper removal."

The bait boxes, which are



recently installed at two ele-

mentary schools.

placed twice a year around a property, are tamper proof and child resistant. They are placed from April to June during the first, or nymphal stage of the ticks, and again in the period between July and September, during the larvae stage.

"The more nymphs and larvae that are killed, the less adult ticks there will be," Mr Whitman said.

"It is a passive approach," he said. "Spraying is aggressive but is done periodically. If you use the boxes, it reduces the need for spraying. You only need one spraying in the fall. It is a stand-alone product for those who don't want to spray, but it works best with spraying in the fall."

He explained the boxes are more convenient because it is possible to install them while children are in school as School Buildings and Grounds Dom Posca.

opposed to spraying, which used to protect requires notification.

Scientists for

The bait boxes break the cycle of young ticks, often smaller than a freckle, being infected by rodents and infecting other animals or people, according to Aventis. There is no danger to a bird of prey or cat if a treated animal is eaten, Mr Whitman said.

Mice and other small rodents are lured into the boxes by bait that is attractive to them. Once inside, their heads or shoulders are coated with fipronil, an insecticide patented by Aventis, the same tick-killing compound

used to protect dogs and cats. Scientists from the Centers

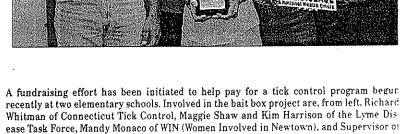
for Disease Control (CDC) began testing the bait boxes with fipronil in the field in 1999, and it was more effective than others that had been tested. A ten-acre test area where 125 bait boxes were spread the first year had 80 percent fewer ticks than an untreated area.

Lyme disease is one of the fastest growing infectious diseases. It is the most frequently reported vector-borne illness in the United States. State health departments received reports of 18,000 cases in 2000, but the

number might be much larger According to estimates by th-CDC, nine out of ten cases gunreported or undiagnosed.

-Bee Photos, Howard

Fifty percent of reported caseinvolve children under the agof 12. Newtown public school nurses removed 118 ticks from children last year. In Newtown, one in four ticks brought in for testing in 2000 carried the bacteria that causes Lyme disease, according to the Newtown Health Department.



What You Need To Know

The typical deer tick habitat is near the ground in wood-ed locations, which makes a majority of backyards and recreation areas in Newtown prime locations for these tiny creatures.

Preparation and prevention are the key to enjoying a healthy, happy summer; Here are some tips:

* When hiking or gardening in particularly wooded, wet areas, wear light colored clothing and tuck cuffs into socks. Inspect your legs once an hour. Once inside, remove all clothing and throw it into a hot dryer for 10 minutes. Inspect yourself carefully, especially warm body nooks such as the armpit, groin, and scalp, and take a shower.

* Ask your doctor or pharmacist about the best repellent products. Those containing DEET are most effective but are not safe on small children; in fact it is not wise to use any of these products on infants and never apply them to your face.

* Inquire about tick repellent lawn services.

It is critical to remove ticks immediately. Follow this technique:

* Use fine-tipped tweezers and grasp the tick near the head

* Pull the tick straight out with steady pressure (avoid twisting).

* Apply an antiseptic to the site once the tick has been removed (note: never use petroleum jelly, gasoline, nail polish remover, or other substances to remove a tick).

* Circle the calendar date when the tick was removed and save it in a plastic bag or cup for identification and bring it to the Heath Services office at Fairfield Hills for evaluation.

Meekunderreporting1996abs

1: J Public Health Manag Pract. 1996 Fall; 2(4):61-5.

Underreporting of Lyme disease by Connecticut physicians, 1992.

Meek JI, Roberts CL, Smith EV Jr, Cartter ML.

Connecticut Department of Public Health, New Haven, USA.

To determine the magnitude of underreporting of Lyme disease, a random sample of Connecticut physicians was surveyed in 1993. The magnitude of underreporting was assessed by comparing physician estimates of Lyme disease diagnoses with reports of Lyme disease sent by physicians to the Connecticut Lyme disease surveillance system. Complete questionnaires were returned by 59 percent (412/698) of those surveyed. Of the 224 respondents who indicated that they had made a diagnosis of Lyme disease in 1992, only 56 (25 percent) reported a case of Lyme disease that year. Survey results suggested that, at best, only 16 percent of Lyme disease cases were reported in 1992. Physician underreporting of Lyme disease underestimates the public health impact of Lyme disease.

PMID: 10186700 [PubMed - indexed for MEDLINE]

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